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ABSTRACT

This feature issue of "Impact" focuses on person-centered planning with youth and adults who have developmental disabilities. Featured articles include: (1) "Centering on People: A Quiet Revolution" (Judith A. Snow); (2) "Look-and Understand-before You Leap" (Brian Abery and Marijo McBride), which describes the basic principles and values underlying person-centered approaches to planning; (3) "Person-Centered Planning: MAPS and PATH" (Jack Pearpoint and Marsha Forest), which describes a process that collects information about and creates a holistic portrait of a focus person, family, or organization (MAPS), and describes an eight-step tool that plans backwards, leading individuals, families, and organizations from identification of a vision for their future to specific actions to get moving on the journey to that future (PATH); (4) "Our Family's Maps" (Bryn, Clark, Lindsay, and Kalli Fortune); (5) "Person-Centered Planning and the Quest for Community Membership" (John O'Brien and Connie Lyle O'Brien); (6) "The True Conductor of Tim's Life" (Karen Holt); (7) "A New Way of Planning for Michael" (Joann Sorem); (8) "Who Can Facilitate Person-Centered Planning?" (Jack Pearpoint and Marsha Forest); (9) "Circles of Friends in Planning with Students" (Gerv Leyden, Colin Newton, and Derek Wilson); (10) "Becoming Dream Catchers; Person-Centered Planning and Youth with Severe Disabilities" (Anne Malatchi); (11) "A Plan Is Not an Outcome" (Michael W. Smull); (12) "Creating Person-Centered Organizations" (Ron Spoelstra); (13) "Living Person-Centered Planning in the Village of Kumbayah" (Shina Asante Ahad and Bahiya Cabral Asante); (14) "Planning for Systems Change in Alaska" (Karen Ward, Gordon Ward, Brenda Ross, Robyn Rehmann); (15) "A Person-Centered Approach to School System Planning" (Ken Woodley); (16) "It's for All of Us, or Not at All"

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(Andy Smith); and (17) "What's Most Important? 'Tis People..." (Te Ripowai Higgins). The issue closes with an 11-item list of resources about person-centered planning. (CR)

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Feature Issue on Person-Centered Planning with Youth and Adults Who Have Developmental Disabilities

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Impact

Feature Issue on Person-Centered Planning with Youth and Adults Who Have Developmental Disabilities

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Using person-centered planning, members of the Fortune family, including Lindsay and Kalli (above), have had the opportunity to voice fears and dreams for their lives, and to plan their futures. See story on page 6.

Centering on People: A Quiet Revolution

by Judith A. Snow

Not so long ago – just a generation – there was no person-centered planning. In the last 20 years, however, a quiet revolution has been taking place in the way persons with disability labels are perceived and supported.

We have begun to believe that individuals who are called "disabled" are first of all people. At one time this thought would have been dismissed politely but quickly; it still is in some places. Formerly, the universal perception that disability invalidated all other characteristics of an individual gave rise to blanket, usually mass, treatment of labeled people. "They" were viewed as dangerous, burdensome, non-human creatures. To have a disability was to be without the capacity for relationship, participation, responsibility or intimacy. Now, some of us are willing to see and support these human capacities in everyone.

We have also begun to believe in and experience the value of planning with individuals. To plan is to believe that the future is not a given, but can be shaped in the direction a person desires. Even more importantly, we are willing to try planning alternative futures that may be better – not just for the individuals themselves, but also for the various communities in which they participate. We dare to carry out our planning in ways that encourage communities to encounter the capacities, contributions, and differences of labeled persons and that benefit as many people as possible.

And, we are not centering our efforts on the caregivers and providers, as important as they are. We are focusing on the individuals who are made vulnerable by being physically or functionally "different." We have created vehicles for discovering and

[Snow, continued on page 26]

From the Editors

We are in the midst of a shift in the delivery of services to persons with developmental disabilities, a shift toward an emphasis on outcomes. That raises a question, however: Whose outcomes? Person-centered planning provides one response to that question. It seeks to create the outcomes desired by youth and adults with disabilities as expressed through a process that uncovers their beliefs, values, strengths, and dreams, and develops action plans to move toward the lives they desire.

As word about person-centered planning has spread, so have mistaken notions about what it is and how it can be used. This Impact presents person-centered planning from the perspective of a number of leaders in its development and implementation, authors who passionately and skillfully describe the values, attitudes, and practices associated with person-centered planning at its best.

An additional note: Herb Lovett, a visionary colleague in the disability field, had agreed to contribute to this issue. Tragically, he died in a car accident on March 21, 1998. We decided that his leadership would not be set aside, so we have selected quotes from his newest book and used them throughout this Impact. These excerpts will, we hope, encourage readers to further explore Herb's wit and wisdom, which is the best tribute we can offer.

What's Inside

Overview of Person-Centered Planning
Strategies for Person-Centered Planning
Personal and Organizational Profiles
Resources for Further Information

The College of Education & Human Development
UNIVERSITY OF MINNESOTA

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Look – and Understand – Before You Leap

by Brian Abery and Marijo McBride

So, your agency or school wants to adopt a person-centered approach to service planning. Why? Because you heard that "it will revolutionize the manner in which the planning of services for persons with disabilities is undertaken" and "people will experience an enhanced quality of life?" Because you think that the individuals you serve will like it, families will be supportive, and people from the county or state will be pleased? Because with the development of natural supports you may save some money?

At almost all levels of the educational and human service delivery systems, organizational change is needed if person-centered planning is to flourish.

What we have above could be a recipe for disaster. Within the past few years, an increasing number of organizations – including schools and adult service providers – have been "experimenting" with person-centered planning. More and more individuals are being trained as person-centered planning facilitators and the lives of greater numbers of persons with and without disabilities are being affected by this alternative approach to traditional service planning. The question we must now ask is whether person-centered planning is really going to change the manner in which we conceptualize and provide supports to persons in need of them, or whether it's a fad that will eventually be replaced by yet another new approach.

We personally believe that if used in the manner intended by its developers, person-centered planning has the potential to profoundly enhance the lives of all persons whom it touches. The concern we have is that many individuals and organizations are attempting to adopt this approach without really understanding and embracing the values and assumptions upon which it is based. As a result, in some cases these tools are being used ineffectively and in a manner other than that for which they were originally intended (i.e., that intention being to facilitate focus persons working together with their circles of support to develop the lives they desire). What can we do to ensure that we use these tools in a manner that supports all people to move toward realizing their personal visions for the future? One answer is that we can understand what the adoption of person-centered planning and service delivery entails, and make an informed decision about whether or not to take the great leap and adopt it.

Why Person-Centered Approaches?

Often, when an organization changes the manner in which it operates, the reasons for the change are thought to be irrelevant. It is the outcome that matters most. However, the "why" that lies behind an organization considering a change to person-centered planning and service delivery is extremely important. "Everyone is doing it," "We think we can incorporate it into our current IHP/ISP planning process," "The state or county wants us to," and "It will make it easier for us to find programs for people" are all reasons for a switch to person-centered planning that we have heard from schools and adult service providers. What's wrong with such motivations?

First, they are contrary to the basic principles and values underlying person-centered approaches to planning. That foundation consists of a focus on persons rather than programs, on the unique gifts and capacities of each individual, on personal choice and self-determination, and on collaboration between all who truly care about the individual. It is not about forcing people to plan for their futures in a manner in which they may not desire, fitting them into available programs, or helping professionals maintain control over the lives of persons they have pledged to support. When person-centered planning is adopted in the absence of a true commitment to the basic values and principles in which it is grounded, in the long-run the organization is unlikely to remain true to supporting individuals to achieve their visions of a better life.

A second problem that often occurs when organizations adopt person-centered approaches for the reasons noted above is that the planning process quickly becomes divorced from the actual provision of services. Although planning may focus on the individual, the provision of services remains system- or organization-centered. In such situations, the only aspects of a personal vision for which one can expect to receive support are those that do not upset the system, that allow it to operate in the manner in which it currently functions. When one's vision for the future does not fit the ways in which things have traditionally been done, when it requires the system to do things differently, it is likely to be ignored or negated.

Person-centered planning requires creativity, doing things differently, and going against systems that in many cases seem more interested in regulating people than ensuring that they receive the type of support and services that allow them to live the kind of lives that they desire. As its developers so often caution, this approach is not just about planning and creating visions, but about assisting people to make their dreams a reality. It is a process that starts and never ends, one that involves an ongoing search for avenues through which individuals can realize their possibilities. This can only be achieved if the entire

process of providing supports – not just the planning – is person-centered.

In examining why they desire to adopt person-centered approaches to planning, it is hoped that organizations will discover that their desire for change is based upon a genuine concern for doing all that is possible to assist others to:

- Discover, celebrate, and further develop the capacities that lie within themselves.
- Become more interdependent and an integral part of the community.
- Dare to dream and work towards a future based upon their personal preferences.

When the desire to use person-centered planning is driven by this set of ideals and values, it is significantly more likely that the resources necessary to support this approach will be available; if they are not, people will create them. It is also more likely that the person-centered orientation will extend beyond planning to the provision of services and to the daily interactions that all members of a person's circle of support have with each other and additional individuals. And, when the question of why one desires to use person-centered planning is answered in the manner above, the probability that those who provide supports will, over time, remain true to its ideals and application is greatly enhanced.

What is Necessary to Support Person-Centered Approaches?

Experts who have studied the manner in which new ideas are introduced into organizations have, for years, realized that it is considerably more difficult to sustain change than to initiate it. Adopting a person-centered approach to service planning and provision is one thing, nourishing it to the extent that it will remain strong and grow is quite another. There is no question that, at almost all levels of educational and human service delivery systems, organizational change is needed if person-centered planning is to flourish. Rules and regulations that seem designed more to protect school districts, provider agencies, counties, and states from liability than to enrich the lives of persons with disabilities need to be dismantled, or at the least implemented in ways that allow for the expression of their intent. This includes ensuring that "adult protection plans," "vulnerable adult status," and other service system regulations and labels are not used to (a) prevent people with disabilities from taking reasonable risks and controlling their own lives, (b) avoid authorizing the more flexible use of funding so that youth and adults have the resources necessary to work toward their dreams, and (c) inhibit supporting the inclusion of persons within their schools, workplaces, and communities.

The manner in which formal supports are provided to persons with disabilities is a second area in which organizational change is needed. This includes clarifying the roles support staff play in the lives of persons with disabilities so that it is understood that they are employees of the people whom they are paid to serve and, as such, need to support individuals to get what they want out of life rather than "controlling" or "programming" them. It also entails giving staff permission to push the limits of the service system, to challenge both internal and external rules, regulations, and policies that get in the way of individuals leading the lives they desire. All stakeholders in person-centered planning and service provision – including focus persons, families, friends, staff, community members, policymakers, and administrators – need to be better educated about the process and its possibilities so that they are able to more effectively collaborate in efforts to help individuals live they lives they desire.

Finally, there must be a long-term organizational commitment to person-centered planning and service provision. This commitment needs to include ensuring that sufficient resources such as time and energy are made available to person-centered planning, creating ongoing opportunities for all parties to listen and respond to the concerns of

[Abery, continued on page 26]

What Person-Centered Planning Is . . .

A set of values and strategies that can be used to assist an individual in creating a vision for the future and a plan for working with others toward realizing that vision.

A process – involving an individual and those who care about that individual – that explores a person's experiences, leads to understanding of the person's core beliefs, discovers the person's gifts and capacities, facilitates listening to and valuing the person's dreams for the future, and results in plans of action carried out to try to make those dreams come true.

A use of planning strategies that focus on people rather than on services or programs, driven by individuals' unique visions, preferences, likes, and dislikes.

A perspective that sees people's capacities, building on the strengths, gifts, and abilities of individuals and their circles of support.

A collaborative effort, involving those who know an individual well and are willing to commit to taking the action necessary to support the person in achieving his or her life vision.

A creative and challenging approach that encourages innovation and risk-taking, which may shake-up the status quo of educational and human service systems.

A fallible process that may not work for all people in all situations at all times in their lives.

An ongoing journey that requires adaptability, flexibility, and support not only during initial planning, but also over the long-haul as plans are implemented, revised, and implemented again.

Person-Centered Planning: MAPS and PATH

by Jack Pearpoint and Marsha Forest

We had great difficulty writing this article. The reason is that we weren't sure we knew exactly what "person-centered planning" really means. Our confusion came from our history.

We developed MAPS and PATH* and used them for several years when some people started to refer to them as "person-centered planning" tools. We know that there is a constellation of such tools developed to help people and organizations make real and meaningful change. They include Individual Service Design, Lifestyle Planning, Personal Futures Planning, Essential Lifestyle Planning, MAPS, and PATH, along with others. Our confusion is that with the popularization of the term, it may be overused, abused, get fuzzy and lose its meaning. We hear many things being labeled person-centered planning that have little to do with the common sense of being focused on human beings. That confuses us. We're comfortable if people want to label the tools we use "person-centered", if they really help meet human needs.

So, we embrace a definition of person-centered planning that says it is a group of methods of action focused on a particular human being (or group of human beings such as families and organizations) who want to create a map or diagram for the future. Using this definition, we have decided to write about what we know best – MAPS and PATH.

Understanding MAPS and PATH

MAPS and PATH, first and foremost, are tools to help restore dreams and ignite hope – and then begin to plan new, constructive futures. For us, MAPS and PATH are not just another way of doing a service or review plan. They represent a different way of thinking.

MAPS is a process that collects information about and creates a holistic portrait of a focus person, family or organization. During the process, participants respond to eight questions that lead the group through a focused reflection, ultimately identifying ways that a community of people can draw together to support individuals to be full participants in directing their own lives. PATH is an eight-step tool that plans backwards, leading individuals, families, and organizations from identification of a vision for their future to specifying actions to get moving on the journey to that future. Both are facilitated processes that involve a circle of people and use visual imagery and colorful wall graphics as integral parts of the planning.

MAPS and PATH are designed as healing tools. They are in fact more spiritual than technical, which is one of the reasons they are difficult to bureaucratize. They must be used with skill and heart, rooted in an ethic of "do no harm." This is not simply a matter of "technique." It is more of an art. There are technical competencies that must be mastered, but this is not the difficult part. It requires first of all an alternative view of our role as facilitators, taking a role of truly listening to people's dreams and nightmares. Next, those hopes and visions must be shaped into sustainable images. Finally, there is a translation into practical daily routines that move us safely in the direction of the dream. It requires giving over control, moving from a position perceived as "power over" to "power with" and "power to."

Using the Tools

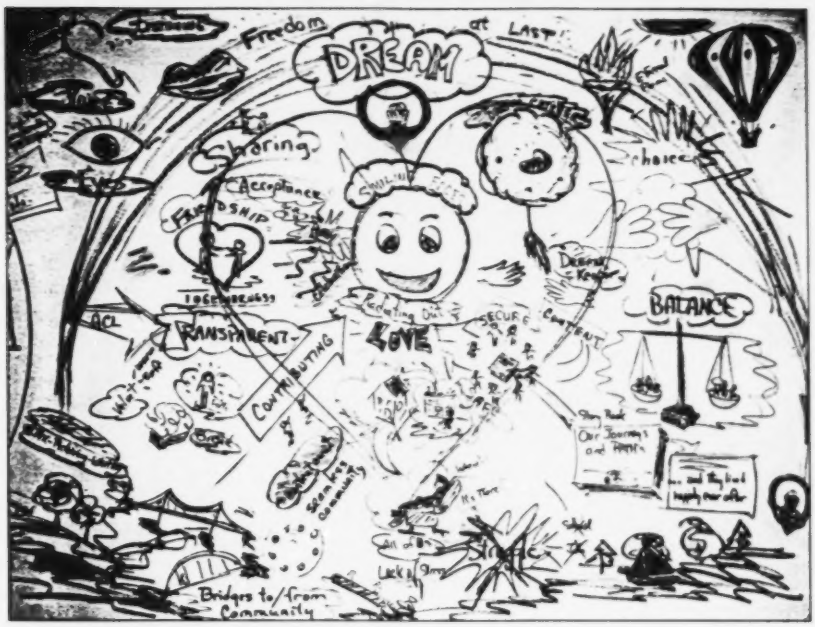
The answer to "when" to use MAPS and PATH is, "When they are needed." We hear people voicing concerns that MAPS and PATH are being mutilated, mandated, perverted, and used incorrectly. It is true. They are. However, the bigger truth is, we have no control over what people do. Thus, our choice is to focus on creating the best tools we can, and providing the most human and thoughtful guidelines and training we can devise in the hope that people using the tools will do no harm. We know that the key problem in the misuse and abuse of tools is not in the design or regulation of the tools, but is in the spirit of the implementors. People who want to exert power over others will use any and all tools to enhance their control. The only controls we can or choose to exert are clear ethical guidelines. Thus, if people with power choose to plan "for" people without having them present, the label on the tool makes no difference, but simply becomes another deceptive shell game to take or sustain power.

There are two preconditions for ethical implementation of MAPS and PATH: *presence* and *listening*. Presence is the first layer of ethical implementation. Those with the skills to make things happen, must "do what it takes" and make sure that the seldom heard voices are heard clearly and in full voice. This means no one ever plans alone. It means someone who has difficulty speaking with words has friends and loved ones with them to ensure that their voice, their ideas, are heard clearly. It does not mean that every whimsical idea becomes a goal. But, it does mean it is not ethical to plan for a person if the person is excluded from the process.

In a MAP or PATH, friends and colleagues struggle together with complex realities and make difficult choices. Good facilitators create a safe space that honors the dreams, nightmares, aspirations, and talents of the focus person. There is no guarantee of the good life. There is no magic bullet. MAPS and PATH are simply tools to help someone create and plan their own life.

Listening is the heart of MAPS and PATH. We believe that actually listening to one another is foundational for these tools. Through listening (not rebutting and arguing) we gather the best infor-

* MAPS – (no acronym) – a MAP is a map. Developed by John O'Brien, Marsha Forest, Jack Pearpoint, Judith Snow and David Hasbury. PATH – Planning Alternative Tomorrows with Hope – was developed by Jack Pearpoint, John O'Brien and Marsha Forest.



A portion of an individual's PATH as drawn by Jack Pearpoint during a planning session.

mation and resources we can muster, then we make the best decisions we can. There are no magical wands. There is just the hard work that all of us must do to realize fully lived lives in these complex and challenging times.

Good facilitators hold empty containers (questions) in front of people, then wait, and listen to the silence. The tension in this silence creates a safe space for people to fill with their deep yearnings and simple unspoken needs – the stuff of life. As facilitators, we hold the empty space in front of the focus person, and ensure that their ideas and wishes are heard. Hearing does not imply agreement, but simply honest, accurate listening to the message. Then the work begins of determining what to do.

Journeying Together

We wish that by designing good tools, and using them well, we could guarantee a healthy positive future – for us and for others. Unfortunately, there is no such guarantee. What we can say is that if we do *not* plan well and work hard, the incidence of abuse and trauma will be higher. We can tell you from our own experience that "being on the journey", engaging in the struggle for a meaningful life, is the best guarantee anyone can offer. No one can promise that anyone will reach a specific goal, but we can at least guarantee that the journey will be a fascinating one. As Helen Keller said, "Life is a daring adventure, or nothing at all!" Choose life!

MAPS and PATH are healing tools on a spiritual journey. They are not just another chart or meeting. With humility, facilitators endeavor to enhance the strengths and capacities of every focus person. To do this, facilitators must create of a zone of safety. People who cannot create a safe place for a person to unfurl their most delicate and fragile dreams and fears should stay away from this type of work. Hearing another's dreams and hopes is a sacred trust. Shattering dreams must not be done! Paradoxically, the art is to balance dreams with doable, positive and possible steps – steps that can and will be implemented by a group of people working together. MAPS and PATH are about creating the links between the dreams we all have (no matter how fragile) and the practical daily steps that begin and

[Pearpoint, continued on page 26]

Taking a New View ...

Over time, I have gradually come to see that people whose behavior is difficult are not clients to be "fixed" so much as freedom fighters – the most vigorous critics of our attempts at service. Time and again, I have worked for people who have either told me directly or whose behavior has said: "These people who work for and around me are nice enough, but what they are doing is either irrelevant or detrimental to my wishes, my happiness, and even, at times, my survival."

My experience has been that extreme behavior often comes from not feeling listened to. Just as repressive organizational or political systems lead to aggression and revolution, the most profoundly disturbing behavior is often found in incompetent and unresponsive service systems.

Seeing people in a lateral rather than a hierarchical relationship opens us to the perspective that all disability is necessarily mutual. If people cannot communicate with words, then we cannot hear them. We might just as honestly describe a person's "learning disability" as our own "teaching disability." Traditionally, the words "handicap" and "disability" have been labels defined and applied by professionals. In a world dependent on authority, such a label has the power to oppress by stealing a person's individuality, and a collective stereotype replaces personal consideration. In a more mutually responsive world, labels would simply point out what people need and become a mandate for our help.

Excerpted with permission from Lovett, H. (1996). *Learning to listen: Positive approaches and people with difficult behavior.* Baltimore: Paul H. Brookes Publishing. Page 6.

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Our Family's MAPS

by Bryn, Clark, Lindsay, and Kalli Fortune

In an attempt to understand the MAPS and PATHS processes for her work in a parent leadership program, Bryn Fortune attended a facilitator's training workshop. She was so impressed with the process, that she signed up the entire family to attend another MAPS opportunity, and complete family and individual MAPS. Below are their perspectives on the experience.

Bryn and Clark

As often happens, unexpected blessings occur when we step out and try new things. As a result of a professionally motivated educational experience, our family wound up with a fresh look at ourselves in an affirming, revealing process called a MAP.

The MAPS process has allowed us to think about and communicate some important feelings and information we often neglect in everyday living.

The experience was powerful, risky, and at times very uncomfortable. In generating our family's MAP, our two daughters each told their heartfelt dreams and nightmares. Both children have significant challenges to their physical health and the youngest daughter has "differing abilities." Relative to other children their age, both have unique perceptions of the world, life, and spirituality. As parents, it was very sobering to hear the girls discuss their health fears, and exciting to hear their dreams of college, boys, and future children.

Lindsay, our youngest at 12 years of age, shared her nightmare. It was about losing her gift to communicate. Her dream was of a huge white mansion with servants, a chef to cook her special diets and make them palatable, an indoor pool, a lake and ski boat in the rear, and a multiplicity of automobiles in the garage. Kalli, our older daughter at 15, dreamt of her own space, a loft in a high location. Later, we found that Lindsay's principal desire for a white mansion was to house the homeless, and Kalli's desire for a loft was to have a safe haven where she could rest, be supported, and be worry-free.

As parents, our principal nightmares were the hell of surviving the loss of the children to physical illness, and being isolated, without the support and love of family. Our dreams were being connected to a large circle of friends, and developing our family's shared sense of faith and of spirituality.

All of these feelings were powerful, very uncomfortable, and risky to announce to a group of people, even if those attending the MAPS session were family and friends. The courage to articulate those things that you fear, the permission to kick back and dream of what might be, and the acceptance of support from those in your MAPS circle are all liberating and stretching activities. As a personal development tool, the MAPS process has shown its strengths. As a family it has allowed us to think about and communicate some important feelings and information we often neglect in everyday living. Each of us feels blessed to have had this opportunity and experience.

As a family, we often pull our MAPS out on the living room floor and talk about the action steps we have accomplished and the ones we are still working towards. We have moved closer to our dreams! The clarity and hopefulness that the MAPS process brings forth is an incredible gift. We encourage every family to participate in the MAPS process because it can truly change your life.

Lindsay

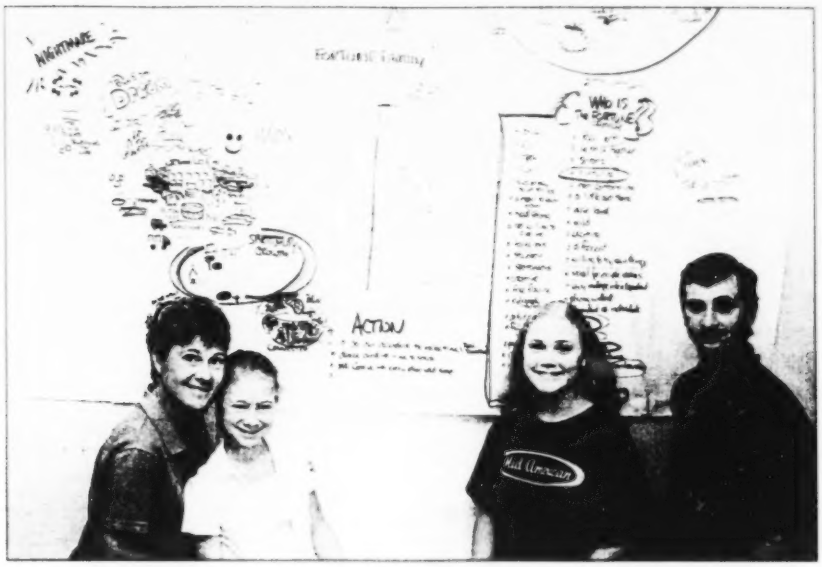
During the MAPS process, I felt a lot of emotions. Some were anger and some happiness. During this time, I was becoming aware of my feelings. I really learned about my path, and that is the main reason I wanted to have it done. I have a strange one, very complicated too, and I felt like it needed to be put down on paper. I learned about my labels, about my hospitalization. I learned about how my parents stood up for me, and said I was smarter than what the school system thought I was.

Through this time, when I was helping with my path and hearing about my path I was having a lot of emotions. It almost felt like you have to be older to handle a path. How old? I don't know, but very mature. Some of the feelings I was feeling were happiness, sadness, exclusion, and madness. With my circle of friends I was able to cope, though, because I was being supported.

My nightmare was kind of tough. I said losing my gift of communication would be my nightmare. But I knew that wouldn't happen. Lots of other parts of my MAP would be a lot easier.

My dream was one of the fun parts. During this time, I felt happy, and joyful. I look at it on the MAP and I see it is possible. One of the biggest things I was dreaming for was a large mansion. My mom always thought it was ridiculous that I wanted one until she found out why. I think during a MAP, people experience emotions, realize opportunities, and much more. I have felt that I could possibly do whatever I wanted to do. And I think that is wonderful.

The last part was goal planning – planning how I can strive to reach my goal. This involved my whole circle of friends. I think this was a very important part because with my planning my goal or dream could be reached. I think that is pretty neat.



Bryn, Lindsay, Kalli, and Clark Fortune with one of their family MAPS.

Kalli

I thought MAPS was a very useful process. With all of my family there, I told my story from my point of view. Maybe they learned some things about my story that they did not previously know. I certainly learned some new things about my sister Lindsay's story when she did her MAP. When we did the gifts and qualities part, it was really good to hear what my circle thought of me. I had never heard so many "warm-fuzzies" about me all at once. That part certainly felt really good.

But not all of it was "feel-good." Part of telling my story was hard. Whenever I got to my disease part, it was hard to talk. However, it was strange, because I felt better after talking about all of that bad stuff. Talking about the nightmare was hard too. I suppose it's because I don't want to face the bad things. I understood that it was a necessary part of the process, so if I ever have part of my nightmare in my life, I can recognize it. I know that the family MAP was really eye-opening. I heard a lot about Mom and Dad that I had never known. I didn't realize that it was such a struggle for Mom to marry Dad because she was leaving her family or that Dad felt guilty about having to stay in Peoria, Illinois, for a little while before he could move up to Farmington with us. They were just little stories like that which really surprised me. I had never thought about any of that stuff.

Doing the family dream was really cool. I had never thought about our family dream, either, so it "forced" me to think about it. Plus, I sort of figured out that we all have a similar family dream.

I would do a MAP again in a flash. It gave me some direction, some plan with where I want to go, some steps on how to do it. I didn't know what to expect when Mom said that she signed us up for the workshop. I didn't know what to expect when I found out that I was going to have my MAP done. But maybe that was okay anyway. I went in to it with an open mind, and came out very refreshed with new knowledge.

The Fortune family lives in Farmington Hills, Michigan.

Taking a New View ...

In the world of positive approaches, we work in collaboration and in a spirit of openness, honesty, and equality. We make decisions by listening to all the people involved (not just the person, the family, or the professionals, but all of them); in the context of the personalities, needs, preferences, and strengths of those involved, we come to some decision. This contrasts with how many services are organized. We may say we are working for the good of people with disabilities, but what that is and how it is to be achieved is decided for them. In many services, we respond to whoever can force us to respond. Too often we make compromises that come from resignation rather than from negotiation. Many decisions are made because of policy rather than because they make sense to the people involved....

Inclusion requires behavior changes, but we have consistently looked in the wrong places to achieve them. Inclusion requires behavior changes of the majority currently content with the status quo. When we professionals assume that people with behavioral differences have to change (and cannot really belong in society until they have changed), we run the risk of becoming the most dangerous kind of protector oppressors: people who not only keep others oppressed, but also insist they are helping while they do it.

Excerpted with permission from Lovett, H. (1996). *Learning to listen: Positive approaches and people with difficult behavior.* Baltimore: Paul H. Brookes Publishing. Pages 233 & 12.

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Person-Centered Planning and the Quest for Community Membership

by John O'Brien and Connie Lyle O'Brien

How can person-centered planning contribute to building communities competent to include people with developmental disabilities as contributing members? Failure to actively and thoughtfully engage this tough question unnecessarily limits the effectiveness of person-centered planning approaches as tools for social change.

The image of a "quest" provides a way to think about the relationship between person-centered planning and community building.

The image of a "quest" – a difficult search through unknown territory for something that seems good to the hero – provides a way to think about the relationship between person-centered planning and community building. The story of a quest answers at least five questions: 1) What does the hero seek, 2) Who are the hero's companions, 3) What are the challenges and aids offered by the territory through which the hero journeys, 4) What prices must the hero pay to continue the journey, and 5) How does the quest change the hero? Each of these questions opens a window on the effectiveness of person-centered planning. We will look through just one of these windows by asking about the nature of the territory through which a person-centered plan invites one to travel.

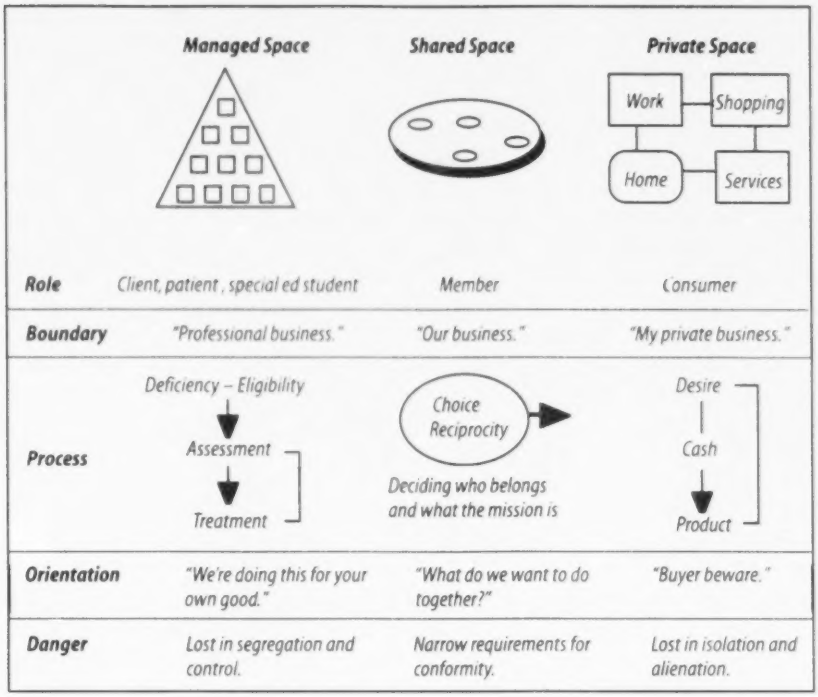
Where does the person-centered planning process point the focus person and his or her allies? What sort of social spaces does the process suggest as places in which unknown troubles might be encountered on the search for what seems good? Obviously, specific answers matter most: In which places and among which people within reach might this particular person find what matters most to him or her at this time in life? However, practitioners of person-centered planning will do well to first take a step back from the specific and consider through which of three types of social spaces the plans they facilitate encourage focus people and their allies to travel.

John McKnight (1995) introduced us to the idea of social spaces and their important effects on social policy, though he can't be held responsible for the use we make of it here. Three types of social space have implications for person-centered approaches to life planning. *Managed space* can be defined as bureaucratic space, highly controlled space that requires dependence and obedience; it is maintained through establishing a stability that can counter challenge to its authority. *Private space* is characterized by individualism and isolation, "going it alone." *Shared space* is interdependent space, where teamwork, collaboration, cooperation, and sharing are practiced. McKnight points out many disadvantages of making policy based on a too-simple map of social life, a map that often excludes shared space and the associations that people create when they assume responsibility for naming and solving their own problems together. Policy often highlights either bureaucratic structures or individualistic pursuits as the sources of good things, weakening community by directing resources into bureaucracies or private pockets, and discouraging people from working together to handle their own difficulties.

Although person-centered planning makes only a modest difference in community building compared with policies that sink billions of dollars into programs that segregate and control people with disabilities, we think it's worthwhile for person-centered planners to make this modest difference, both for the real benefits to the people involved and for the lessons their experience can teach receptive policymakers. So we suggest that person-centered planners review their work by asking, "Do the plans I facilitate focus people's attention primarily on journeying through managed, private or shared space?"

A quest that stays in managed space is a search for more comfortable clienthood or more powerful professional interventions. It does not disturb the physical and social distance that separates people with disabilities. It asks for better use of the professional authority over people built into program structures. The quest concludes when staff adjust what they do to better accommodate the person within a service. Assisting a much anticipated trip to Disneyland, assigning a paraprofessional to support a student in a general education class or getting approval for a transfer from an activity center to supported employment could each be worthy goals of a quest that stays in managed space. The challenges on a journey in managed space include programs designed with the assumption that people will adjust to fit them, inflexible readings of regulations and budgets, and staff fear that change might involve heightened liability, conflict or inconvenience. Help will come from personnel who identify with the focus person's desire and decide to create the flexibility to accommodate it.

Partly in reaction to dependence on staff benevolence for journeys in managed space, some reformers link person-centered planning to self-determination, a system change that increases people's control of an individual service budget. This places the focus person in the role of service consumer and sets free the



inventiveness of journeys in private space. In this space, the key question is, "How do you want to live (given the limits of your budget and the kinds of supports that are offered)?" A journey that stays in private space finishes when the customer is satisfied enough with the service product to close negotiations. This shift in the balance of power creates new responsibilities: the consumer must become informed enough to have a basis for evaluating and negotiating a service provider's offer and delivered services; the consumer must find ways to stretch or adjust the individual budget when the cost of their requirements for assistance changes; the consumer must become an effective employer of support workers; and the consumer must decide how to live. These journeys challenge allies about when and how to try to influence the focus person's decisions or confront the person about apparent problems. Help comes in the form of small breakthroughs as the focus person realizes the excitement of having and solving daily problems. Help comes when the focus person, his or her allies, and the people who provide assistance recognize their interdependence as a source for creative problem solving. Help comes as difficulties give people the occasion to live up to their trust in one another.

Quests into shared space usually pass through managed space or private space, but don't stop when services improve or customers are satisfied. Travelers in shared space search for understanding of the gifts a person can contribute to the common good, and for opportunities to make those contributions. This search attends to who a person becomes beyond being a client, student or consumer, and how a person wants to use their freedom. This sort of quest may sound a bit grand, but usually it is simple. A passion for nature leads to a semi-formal group that spends Saturday mornings cleaning up a polluted creek. Concern for homeless people leads to week after week of volunteer work in a shelter kitchen. A family heritage of making church music leads to a place in the choir. A gift of hospitality leads to parties that gather and expand groups of friends. Hunger for justice leads to a job organizing people with disabilities. Interest in local politics leads to hours of envelope stuffing. Some challenges on journeys in shared space arise in refining understanding of the person's gifts, especially when those gifts are buried by years of low expectations and imposed passivity. Help with these challenges will come from imaginative listeners who are willing to check their intuitions by inviting and supporting the focus person to try something new. Other challenges come in arranging the assistance a person needs to participate: getting rides, assuring that a person has the help necessary to be up and dressed on time, and making room in the schedule for a person's memberships. Help here will come in the form of service workers who are willing to join in the quest. Still other challenges come as people cross the boundaries that form the invisible bubbles that can contain even a person who is present to community life. Help in these negotiations will come from people whose sense of hospitality and appreciation of a person's contribution draws them past unfamiliarity and awkwardness into mutuality.

Any quest that overcomes our dismal history of segregation and control deserves honor, regardless of the social space through which people journey. Not everyone who wants a person-centered plan will want to undertake a quest in shared space. But, we believe that shared space offers the greatest opportunity for person-centered planning that encourages people with disabilities to break out of the invisible bubble that too often seems to separate them from their communities. And the more ready education and human service providers become to join in building community, the more they will find people with disabilities who are ready to join them.

McKnight, J. (1995). *The careless society: Community and its counterfeits.* New York: Basic Books.

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The True Conductor of Tim's Life

by Karen Holt

"Hear ye, hear ye. Tim's Annual Sacred Ceremony is now called to order." The interdisciplinary team professionals are assembled around the conference table with pens and paper at hand. Someone speaks: "All in favor, raise your hand. Good, it's unanimous. We've decided on Tim's goals based on his deficits. He will learn hygiene, dusting his dresser, table setting, and the art of cooking hard-boiled eggs. Will someone please bring him back to the room to sign the forms that indicate his presence, participation, and approval of the program plan?"

Tim was one of the first individuals at New Directions to participate in the person-centered planning process.

Four years ago, New Directions, a residential service provider in St. Paul, Minnesota, made the decision to shift away from such methods of planning and services and toward an approach grounded in person-centered planning processes. Individuals with developmental disabilities are now the conductors of their lives, with the service providers performing as their orchestra, assisting them to live a life of their own choosing.

As adopted by New Directions, the person-centered planning process begins with the formation of a Quality Circle of support. Individuals select those with whom they feel close and who are motivated and committed to supporting the changes they desire in their lives. Helping individuals identify their hopes, dreams, strengths, and gifts, along with what and who is important to them, becomes the starting point for discovery. Gathering this information initially takes place during meetings over the course of two days, three hours per day. This is an energizing and emotional process in which the individual and group members share information that may have been unknown. There is frequently laughter and tears as they move toward a plan of action to make the individual's life vision a reality.

Tim was one of the first individuals at New Directions to participate in the person-centered planning process. Under the traditional system of planning, he wasn't very involved in decision making. Discussions frequently focused on his challenging behavior at home and work and how it could be "fixed" with programming. He became very good at nodding his head in agreement to things he may not have truly understood.

His lifestyle at the time consisted primarily of sleeping as much as he could. He became angry if awakened for meals or activities. His friends were primarily his housemates and a few coworkers. He spent much of his workday sitting down on the job at a local fast food establishment because he was so tired. He was close to losing the job because of angry outbursts toward others.

It was decided that a person-centered planning approach would be used to address Tim's needs and desires. He sent out invitations to his county case manager, specific residential and day program staff, and his parents asking them to be part of his Quality Circle and to participate in his first person-centered planning gathering. At the gathering, Tim showed everyone present some of his most wonderful gifts and talents as he became a quick-change artist and put on different costumes that accentuated his various interests. It was discovered that Tim's interests had to be explored in a creative and energized way. The Quality Circle, with Tim in charge, went to work brainstorming.

One of Tim's interests was All-Star Wrestling. A Circle member knew of a gym that was run by an all-star wrestler, and so plans were made to introduce Tim to the wrestler and assist him with becoming a member of the gym. Attending the gym two days a week is now a regular part of his routine.

Tim also expressed an interest in dressing up in a Santa suit and entertaining others with his hearty "ho-ho-ho." Again, brainstorming proved fruitful; Tim was introduced to the Salvation Army and a volunteer Santa opportunity arranged. Every December since Tim has put on his Santa suit and delivered hot cocoa to bell ringers around the city. He also delivers Christmas cards in his Santa suit to people in a nursing home. Through this, he has developed a friendship with a woman who lives in the nursing home; he visits her regularly, goes out to eat with her, and occasionally entertains her at his home. She is now a member of his Quality Circle.

Tim also has been connected to the local Jaycees chapter, attending monthly meetings and participating in volunteer activities. He is a welcome face at Jaycees social events, and it has become an annual affair for the Jaycees to celebrate Tim's birthday by bringing beer and cake to his home.

Because Tim's enjoyment of life and energy level have increased, his work performance and attitude have shifted dramatically. He recently was promoted as head of the crew at his job. This and other wonderful things that are going on in Tim's life didn't happen overnight. There has been an ongoing process to bring the Quality Circle together as his dreams and plans have been realized or changed. The Quality Circle continues to brainstorm how to improve his life in ways he desires. Tim is now the facilitator of his Quality Circle gatherings, and the true conductor of his life.

Karen Holt is a Social Worker with New Directions, St. Paul, Minnesota. She may be reached at 651/488-0397.

A New Way of Planning for Michael

by Joann Sorem

It was not easy to "see with new eyes" what life could mean for my son Michael. As his 36th birthday approached, I was asked to attend several meetings in which Michael and some people who knew him were to brainstorm and talk about how he wanted to enrich and expand his life. During the meetings we shared some of the stories about Michael and our struggle to get the services and supports needed to live a normal lifestyle. Some of the memories were long forgotten, and I left some of the meetings with headaches from revisiting sensitive and intimate parts of our lives. Michael and I both needed a lot of support and encouragement to become so vulnerable again after years of just moving along the service delivery system with all of the rules and regulations. There is some safety and security in doing and thinking the same old way. But, it was time to try something new.

Michael seemed isolated and protected in his group home. We knew he was social and liked people, but he had limited opportunities to be with family and make new friends. How could the environment, staff, and family become more "Michael-friendly"? Identifying his preferences, wants, dreams, and needs was the first step. Supporting him in fulfilling his wishes was the second.

Michael, who is non-verbal, let us know the things he did and didn't like through his behavior, gestures, and utterances. We also gathered information through observing him and talking with people who knew him best. Among his identified likes were friends, family, and motorcycles.

As his birthday approached, we wondered, in response to his desire to spend more time with friends and family, "Why not invite some new friends and extra family to Michael's home for a party with pizza and birthday cake?" So, Michael and his circle of support began inviting people. A staff person from Michael's work program suggested that her sister would probably like to meet Michael, and she attended. Inviting some cousins who hadn't seen Michael for a long time, a neighbor, and his barber of 15 years seemed like a good idea, too. Michael enjoyed the party and seemed to feel comfortable with the gathering. He even asked his staff person's sister to sit by him at the table when he had his birthday cake.

Michael (back) enjoys one of his loves – riding on motorcycles with "the guys."

Easter followed Michael's birthday. His group home staff had been bringing him to the church that our family attends as part of supporting him to make new friends. Building on this, after Easter services Michael had dinner at home with family members that he didn't know very well. He also had the chance to act on one of his other likes – motorcycles. He learned to ride (slowly) on the back of the same motorcycle that I had recently just learned to ride on. He liked the freedom and independence that allowed him to ride with "the guys."

With limited speech and a higher than average activity level, it has been hard for Michael to make new friends and share interests with others. So, he has sent out a letter to new friends, acquaintances, and family members to tell them more about himself and what he likes to do. He was surprised to receive letters and pictures back – and now keeps them in a personal album.

Trying new social skills, improving communication, having more opportunities to be with family and friends, and finding the right medication have all changed the quality of Michael's life. He has become more adventuresome and willing to try new things. He also expresses much happiness and joy when he spends more time meeting friends and being with family. And, he has had more experiences that other young men his age have, especially social, cultural, sports, and leisure activities.

Continuing the process of person-centered planning takes time, commitment, energy, a facilitator, and well-trained staff. Good communication is essential on a regular and informal basis. Support for Michael and those who love him is also part of the process. Finding and adding to the support group of friends, family, professionals, staff, and community members needs to be ongoing. Person-centered planning is a "people process" bringing together people who care about Michael and are willing to see him "with new eyes."

Joann Sorem lives in Bella Vista, Arkansas, and Michael lives in St. Paul, Minnesota.

Who Can Facilitate Person-Centered Planning?

by Jack Pearpoint and Marsha Forest

Can everyone facilitate person-centered planning processes? That is like asking if everyone can do brain surgery. Opening people's hearts and dreams is surgery on the soul. It is delicate and difficult work, and must be honored with skill, compassion, and love. If you discover that these are not your strengths, then find other people who *are* skilled in doing this work and let them undertake it. We have seen magic happen when person-centered planning tools are used with skill, love, imagination, and humility.

Opening people's hearts and dreams is surgery on the soul. It is delicate work and must be honored with compassion, with skill, and with love.

For us, the heart of person-centered planning is, "Facilitator – know thyself." Here are a few guiding questions for facilitators to ask themselves:

- Have you experienced being the focus of a MAP, PATH or other person-centered planning tool?
- Do you have a mentor, guide, therapist, or circle you see regularly to check out your own life?
- Do you read and study continuously in group dynamics, organizational change, healing, health, etc? Do you read outside your own field to increase your scope?
- Do you think you have been fully trained and certified by taking a workshop or 3-day course? If so, return to # 1 above (have you been a focus person?).
- Do you alphabetize processes like PCP? Please don't. The initialized version trivializes a deep issue. We don't want people reporting that they were PCP'd upon.
- Do you work alone or do you have partners with whom to share experiences and reflect on your learning?

Good facilitators struggle to balance many seemingly paradoxical issues. The following are four we've experienced:

- *Learning and Unlearning:* Facilitators must constantly learn new things, and unlearn some old ones. The facilitator is a servant to both the process and the person, holding empty containers and drawing the content out of the person and his or her friends, family, and colleagues. The plan belongs to the person, not the organization or the facilitator. We must learn to hand over power – and unlearn our "control" habits.
- *Knowledge and Self Knowledge:* One must have a wide knowledge base – and a strong, knowing sense of self. As a facilitator one must give up preconceived notions of what is good or bad, what is possible or impossible. This requires knowing ourselves – our strengths and limits – so we can distinguish between our personal preferences and those of the person we are serving. Dangerous facilitators override another's words and images with their own interpretations.
- *Professional and Personal Integrity:* There is no separation between personal and professional integrity. Integrity is integrity. Separate ethics harms people. To minimize this risk, our ethics rule is that facilitators must practice these tools on their own lives before using them on others. This makes us more respectful and less dangerous.
- *Self-Reflection and Review:* We must constantly reflect and review what and how we are doing with these tools. Just because we have learned the process does not mean we are doing our best. There is always room for improvement. Maybe we are overtired, or perhaps due to personal preferences we are not the right people to undertake a particular MAP. We must listen to these "itchy" patches and pay attention.

We feel it is unfair at best and obscene at worst to ask others to dream and be vulnerable while we remain aloof – hiding behind the mask of so-called professionalism. A brilliant professional is one who has explored his or her own soul and knows the boundaries necessary to allow others to share their pain and joy without intruding into or invading their space. We tell people, "Beware of facilitators who advise you what to do, but whose own lives are a gigantic mess and can't ask for help themselves."

There are times when doing "nothing" is a discerning decision. Better to be humble and nervous about your capacities than to leap into unknown waters and do irreparable damage. This is not an excuse to never take a risk, but rather a reason to be cautious with other's lives. Respect them. There are times to stop a process mid-stream. Do no harm! Take risks, but choose the time, the place, and a tool that give an excellent chance of success. And know your own limitations. That is all any of us can do.

Jack Pearpoint and Marsha Forest are the founders of the Centre for Integrated Education and Inclusion Press International, Toronto, Ontario, Canada. For further information on MAPS and PATH, as well as information about facilitator training, contact them at 416/658-5363 or by e-mail at 74670.1124@Compuserve.com. Or view the Inclusion Press website at http://inclusion.com.

Joel Hollands facilitating Marijo McBride's person-centered plan (PATH).

Profile of a Facilitator: Joel Hollands

Joel Hollands and I first met almost a year ago at a Creative Facilitator course sponsored by the Centre for Integrated Education in Toronto, Canada. The course was designed to build strengths and capacities in person-centered planning facilitators. Joel was my PATH (Planning Alternative Tomorrows with Hope)* facilitator. This was a milestone for us and the PATH process – to have a 13-year-old young man facilitate.

At first I was concerned. I knew that person-centered planning should not be taken lightly. When done right, it looks effortless. When done wrong, it can have far-reaching, detrimental consequences for focus persons, their support networks, person-centered planning, and beyond. What I came to realize as Joel facilitated my PATH was that process facilitation is an art that can transcend age as long as the facilitator demonstrates mature judgement and behavior, is grounded in the philosophy and core values of person-centered planning, honors the uniqueness of the focus person, is a good listener, elicits the focus person's dreams and ideas rather than their own, is flexible and creative, and creates a welcoming environment. Joel possesses all these traits.

Joel has been involved with the PATH process since he had his first PATH done in 1996. In his own words, "The topic of my first PATH was for me to create my perfect school year. I wasn't having a very good year at school. In my dream school, I remember saying that kids ran to school because they were so happy to go. The school wasn't cramped and teachers put themselves in the students' shoes. The NOW part of my PATH was that teachers didn't care about me and wanted to leave school as soon as possible just like the students. My PATH helped me realize it would be a good idea to change schools and try something new. I didn't do all the little steps I said I would do, but I did the big step and I moved to a new school where I am very happy. I was chosen to do the valedictorian address for the school."

Joel asked for the opportunity to do graphic facilitation for another's PATH at the Centre's Inclusion Summer Institute. A graphic facilitator captures the focus person's dreams, values, and action plan in pictures and words on large sheets of poster paper. Joel recalls, "I decided I really liked to do graphic facilitation and asked to do some graphics with an adult partner. I was really nervous as I wanted to make sure to get down what the focus person wanted and I didn't want to mess it up. I wanted it to be perfect. I was very cautious and I learned that was good as I got down the focus person's images and thoughts, not mine. After being the graphic facilitator, I decided I wanted to learn process facilitation by participating in a Creative Facilitator course. I did my first process facilitation as a team member with another facilitator. The PATH finder was Marijo McBride. I had to make her focus on her path and had to get down everything she really wanted to say. "

In facilitating my PATH, Joel encouraged me to unlock possibilities in my life and develop a plan to make my dreams a reality. The PATH, through the strength of effective facilitation, has given me permission to dream, plan, realize dreams, and dream some more. I will continue on my evolving journey through the support of person-centered planning, my circle of support, and effective facilitators like Joel.

Joel loved doing PATH and says "I'd like to try MAPS, but I know that the first rule of thumb is that you can't do it to anyone else till it's been done to you because you can't understand what another person is going through unless you've done it yourself." He took the next step toward becoming a MAPS facilitator this past summer when he had his MAP done.

* PATH is a person-centered planning tool developed by Jack Pearpoint, John O'Brien and Marsha Forest. It is published by Inclusion Press in Toronto, Ontario, Canada.

Contributed by Marijo McBride and Joel Hollands.

Circles of Friends in Planning with Students

by Gerv Leyden, Colin Newton and Derek Wilson

One of the challenges in beginning person-centered planning with students who have disabilities comes from their history of social isolation. Even in schools where students with and without disabilities learn together, there often still remains a social barrier that leaves students with disabilities without close friends and companions among their school mates. When introducing person-centered planning with such students, there is the question of who will participate in their planning process. Often, it is family members and school staff. But, that leaves a gap in the area of peer support and involvement, and limits the resources available to enhance a student's social inclusion. How can that gap be closed? One way is through using a Circle of Friends.

A Circle of Friends is a group of people, including age-peers, who respond to a request for involvement in the life of an individual who needs the friendship and participation of others. Participants in a Circle may volunteer to be part of the planning and support team for an individual undertaking a person-centered planning process. They may also be a network of people willing to befriend a person, get to know them, spend time with and care about them, and share activities and interests.

To create a Circle of Friends in preparation for person-centered planning, preliminary work needs to take place. In our case, we utilized the Circle of Support building activities described in *The Inclusion Papers* (Pearpoint, Forest & Snow, 1993). The starting point is the setting forth to a selected group of students the need for a Circle, a discussion usually initiated by a teacher, educational psychologist or school counselor. Then, those who volunteer begin accompanying the individual on a journey to create the life he or she desires.

The following list of frequently asked questions about Circles of Friends sums up the excitement and anxiety of teachers, parents, and educational psychologists who have attended our workshops on inclusion, and who have little experience of person-centered planning for vulnerable students. We offer them here in hope that they may answer some of the questions in the minds of those reading this article. One note of caution: The answers are our answers, not "The Answers" or even your answers. We cannot know what will work best in your context. As long as one eye is kept fixed on the deeper values and principles underlying person-centered planning, you can be creative in finding your own ways to build relationships and community.

What if no students respond to the invitation to be part of the focus student's Circle?

This is probably the most frequently-voiced anxiety from anyone contemplating a Circle. Often, this fear is fueled by adults who may have experienced considerable frustration when trying to change the student's behavior or placate other pupils who have been made angry or fearful by the focus student. Yet our experience is that this fear is never realized if the facilitator has recruited the right people and asked the key questions from the heart.

Sometimes the pre-Circle session will be used by individual pupils to express their anger and frustration with the focus student. As long as the facilitator provides a safe boundary to contain these strong feelings and does not allow the session to become solely about complaining, it is invariably helpful. The message is that this is real, people are being listened to, and the class is now able to move on and look at constructive ways to help the focus person.

If, at the stage of enlisting support, the process appears sluggish, it is often helpful to put the recruitment issue back to the group by asking, "Is there anyone who people think would be a helpful member of the Circle and who hasn't yet come forward? " Groups always have suggestions and they are usually right!

I can think of at least seven students in my class who would benefit from this approach. Should I run a Circle for each of them?

We doubt whether this would be manageable for one facilitator and we recommend that a Circle has no more than one focus person within it. Perhaps this question is really about unmet social and personal needs among students in the class or school as a whole. If so, one way forward is to ask for help from the students themselves. All of them! If a Circle already exists in the school, its members may provide useful suggestions of where and how to start.

What if disclosures are made during the Circle meetings?

It is important when briefing a new Circle to ensure that all members realize that they may be told something which they cannot keep secret or confidential. Students will need to be reminded that if this occurs they should speak to an adult such as the teacher facilitating the Circle. One of the strengths of Circles is that pupils do learn to trust one another. In our experience, secrets and private sufferings have been safely shared and appropriately contained in most Circles.

Can Circles co-opt members?

Stronger, older peers, siblings or even adults may usefully be co-opted into the Circle and strengthen its work. Diversity brings strength and this is at the root of Circle work. The guiding rule is that the "right people" who can make a difference to the individual need to be present. Sometimes the right person is the one giving the Circle most concerns because of his or her antagonism towards

the focus student. A constructive way of viewing this antagonism is to say that this person also has an unmet need to belong. An invitation to be part of the Circle is one step towards meeting this need and dealing with the antagonism.

What is the best way to choose the Circle members?

In our workshops, we generally discuss the pros and cons of a number of ways of selecting members, including selection by students, facilitator and students, or by focus student. If using selection by students, the group nominates those whom they feel are best suited to support the focus young person. They can be prompted to consider shared interests, hobbies or other strengths of fellow classmates (e.g. listening skills, personality, communication skills, popularity and "street cred"). When using selection by facilitator and students, the facilitator chooses two students on the basis of their contributions to the discussion, two more members on the basis of their knowledge of the group, and the students choose the rest. This is the method we prefer, but it may not be right for you. A third option is for the focus student to select from volunteers. The focus student is given the names of volunteers and asked to suggest who would be most helpful, supportive and usefully challenging within their Circle. This provides maximum control for the focus person and strengthens his or her ownership of the process.

How long do students need to remain members of the Circle?

We have already stressed the need for the facilitator to provide safe personal boundaries for Circle members. Time boundaries are equally important and it can be helpful to let prospective Circle members know that a lifelong commitment is not expected! In our experience, a school term is a useful time span. Following that period, Circle members will have the choice of continuing for a further period or of opting out for a spell. In practice, we find that opting out is rare in successful Circles. However Circle members, particularly at the secondary or high school level, find it reassuring to know they have a choice.

Can the Circle meet without the focus student present?

Meeting without the focus student present is not an option that has any legitimate place in Circles work. The Circle is built around the focus person who has the final say on decisions and the power to influence events. This is unlikely if he or she is not present. In practice, much depends on the skills of the facilitator and his or her ability to enable difficult issues to be aired constructively. When facilitators feel the need to convene a Circle meeting without the focus person present, it generally means that things appear to be going badly and the efforts of members are ineffective. It may be helpful to provide a chance for members to offload frustrations if the alternative is the demise of the Circle. But frequent Circle meetings without the focus student indicate that you have strayed way off track and are no longer facilitating a "Circle of Friends."

What if ..... ?

The potential range of questions is endless and we need to remember that full community participation is seldom achieved through "quick fix" values or tools. The facilitator needs to plan for coping with periods of disappointment and crisis as well as the fulfillment of seeing the growth of positive social connections and friendships for the focus person. If there is an answer to the unexpected or unexpectedly prolonged crisis, it is that sometimes we have no idea what the way forward is. This answer is a counsel against the culture of professionalism that implies that every situation is covered, every question has an answer if only we knew to whom we should refer. To be able to say with honesty that you don't know what to do next is often quite therapeutic. It passes the power back to the person seeking help.

"An ounce of prevention is worth a pound of cure," so it makes sense for individuals within Circles to avoid vulnerable situations. Escorting a vulnerable student home, visiting at home, playing in an isolated area and so forth may be risky and it can be safer to 'buddy-up' or arrange back-up.

Similarly, if facilitators are to sustain Circles through times of crisis, they also need to draw on their personal and professional support networks. When running a Circle in a complex organization such as a school, it is wise in advance to choose as back-up someone with relevant consultancy and group leadership skills. This might be a trusted colleague, educational psychologist, advisory teacher, social worker or representative of a voluntary body. Remember, "Never dive alone!"

Creating Circles of Friends inevitably involves risks. Human relationships involve risks. More and more of us are prepared to be innovative and take those risks in order to bring students with developmental disabilities from isolation into participation. The risks of doing nothing or following tired professional routines seem to us far greater and unjustifiable.

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Becoming Dream Catchers: Person-Centered Planning and Youth With Severe Disabilities

by Anne Malatchi

Many of us are familiar with the Native American legends surrounding dream catchers. The Sioux and Ojibway Indians, along with many other tribes, consider the dream catcher the web of life, and it is hung above the bed or in the home to sift the dreams of those nearby. Good dreams are captured and stay with a person; bad dreams escape through the hole in the web's center and leave the person's life. Our challenge, as professionals who care about and support youth with dual sensory impairments and severe disabilities, is to become dream catchers. We can do this through using person-centered planning as the process to journey with youth, their families, and friends on a voyage of discovery that involves learning about their dreams and nightmares, really listening to their choices, and guiding them toward a life of their choosing.

At Together We Can we work with schools to help them move toward using person-centered planning in the IEP process with youth who have dual sensory impairments and severe disabilities. In the past, our educational system appeared to be designed to support a system-centered approach, not a person-centered approach. Schools became label driven and label crazy, and this was especially evident during IEP meetings. Often, during the meetings students were referred to by their labels, and it was the labels that drove decisions, planning, and placement – not the individual. This is the opposite of person-centered planning.

In our work, we are often asked how we can be person-centered if the person we are educating cannot see, hear, or communicate with us? It is possible, but we should begin early. Waiting until transition time and the age of 14 or older is often too late to begin listening to young people's dreams and finding out about their journeys toward lives of their choosing. Consequently, we believe that person-centered planning should be used in developing IEPs beginning in pre-school and elementary school. This requires changing the belief that the educator is the only expert and in control of all educational decisions, to a belief in a collaborative, transdisciplinary team approach to education and decision making. A collaboratively developed IEP can be the first step toward shifting from a system-centered approach to a person-centered approach in educating students with dual sensory impairments and severe disabilities.

One student with whom we've seen person-centered planning work as a dream catching process is Susan*. Susan is 17, very social, has a job, and enjoys hanging out with friends. She is also DeafBlind and communicates using sign language. However, due to her vision impairment, those individuals signing to her must be within her vision field. Additionally, her slow processing time and weak fine-motor skills impact her ability to understand and respond.

For many years, Susan's IEP team had focused on her labels: DeafBlind and Severe Disabilities. Programming, supports, and placement had been determined more by the "severe disabilities" label than the combined loss of vision and hearing. Her parents have educated themselves regarding DeafBlindness and Susan's other disabilities, and have spent many hours educating others on the IEP team about her strengths and weaknesses. The team is now beginning to understand the importance of listening to Susan and her family, collaborating on decision-making, and seeing her unique strengths and capacities.

Susan wants desperately to have friends with whom she can communicate, to work in a restaurant, to be safe, and to know what is going on around her. Her IEP team has taken a major step forward in acknowledging her needs and desires and agreeing to a type of support system that is unfamiliar to them. This school year she will work on transition skills in the community, at her high school, and at her job site with the support of an interpreter/tutor. The interpreter/tutor – much different than a traditional interpreter – will provide the "eyes and ears" that Susan needs in order to access her environment. With this one-to-one support, she will be able to be aware of what is happening around her and move toward a life of meaningful participation in her community.

Creating collaborative IEP's is only the beginning – a beginning of a lifetime journey for individuals with dual sensory impairments and severe disabilities that must involve the principles of a person-centered education. It is a journey that along the way will force those that support, guide, and educate, to look at themselves first in order to seek new ways to listen, instead of always seeking ways to change the students. It is a journey that focuses on dreams and visions for the future and on what needs to be taught in order to get there. Making a commitment to becoming a dream catcher is a necessary precursor to this kind of person-centered planning and educational process.

* Pseudonym

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A Plan is Not an Outcome

by Michael W. Smull

Person-centered planning is our label for learning how people want to live now, what is important to them in everyday life, and how they might want to live in the future. But, a plan is not an outcome. The only reason to do the planning is to help people move toward the life that they want, and person-centered planning is only the first part of that process. Whether anyone can "get" the life described is also determined by their access to resources and the "rules" for using those resources.

Implementing plans is about supporting a journey – a journey that includes recognition that what we want changes over time, that choices often have to be made about which of our competing desires to satisfy, and that many of us want more than our resources can sustain. We begin by listening and trying to understand what we hear. We record what we learn in a plan. As we act on what we have learned, we see how it works. And then begin again by listening and understanding.

Moving Beyond Present Reality

For most youth and adults with disabilities who receive services, the present reality is a world of programs. Most of the current resources are fully committed to buy capacity, to buy "slots." There are people living in group homes and going to segregated day services who have told us that they hate their roommate and are bored during the day. There are high school students attending educational programs that they find meaningless because they don't prepare them for the future they desire for themselves. Where people want change, planning without real action simply creates cynicism for everyone. One of the traps that this creates for planning is that what is available now shapes what is asked for.

In trying to not be limited by what exists we have learned that the kinds of questions that you ask and the order in which you ask them make a difference in the outcome. Ask about what is important before asking where it could happen. Learn what is important in everyday life and then look at all the different ways that it could happen. We now have enough "best practice", enough "pilots", so that what people have in mind is likely to already exist. It may not be next door, it may have been developed in another country, but it is likely to exist. Only after people have explored what is possible should they look at what is available now. In locations where that which someone wants is not offered, the next question – "How do we develop it here?" – can be answered knowing that it has been done elsewhere and that there are resources from which to learn.

Asking for Input

Clearly it is easiest to create new supports with people who are just coming into the community system, people who are leaving their family homes or are leaving institutions. When we plan with those people who are already receiving services we are facing a number of new challenges. One of these is that people are not used to looking outside of their current ways of doing things. Plans that started with what was wrong with someone were typically part of a professional ritual where "good paper" counted more than good lives. These plans were written with those who spent the least time with the person having the greatest input. They were read only by those who wrote them (and those who inspect), and were not used in everyday life. This part of professional culture continues and interferes with implementing person-centered plans. To change the culture we have been recommending that those who manage or visit ask some simple questions after the person-centered plans are written. Ask those being supported and those providing the day-to-day supports: How is the plan

[Smull, continued on page 27]

Taking a New View ...

The hierarchical, competitive culture in which most of us have grown up dismissed people with disabilities as "deficient" or "defective." In that world, an important question was: What is wrong with that person? Enormous effort – obviously – has gone into answering that question about people with disabilities. What we have slowly come to recognize is that this question, ultimately, can be applied to all of us. Inevitably, in such a culture there is something "wrong" with everyone, so if we really want a society for us all, we need to turn the question from "What is wrong with you so that you can't be a full member of society?" to ask instead, "How have we collectively built a society that keeps you out? What do you have to bring? What has your life taught you and what can we learn from you?"...

People with disabilities are in the early stages of a liberation movement – they are beginning to recognize that their lowly status in society is due not to their disabilities but to an unjust society. Until this awareness gains wider currency, however, most people –all kinds – will see the status quo of oppression as "right." When people labeled retarded are seen as defective, it makes sense to assume that they cannot be included fully or valued equally in society. Custodial and paternalistic attitudes are seen as protecting the vulnerable rather than stifling untapped and unexpected abilities.

Excerpted with permission from Lovett, H. (1996). *Learning to listen: Positive approaches and people with difficult behavior.* Baltimore: Paul H. Brookes Publishing. Pages 7 & 10.

Creating Person-Centered Organizations

by Ron Spoelstra

Community presence. Community participation. Competence. Respect. Choice. These five concepts form the basis of any strong person-centered planning process. We are well on our way to offering truly person-centered planning to those we serve when these five concepts characterize our organization's culture. Let's take a closer look at the five – originally articulated by John O'Brien (1991) – and their roles within organizations serving people with disabilities.

Community Presence

Person-centered planning usually addresses the "presence in community" of a person with a disability. It includes creation of a MAP or other personal profile that looks at where the person is socially connected and disconnected. The focus is similar when an organization wishes to become more person-centered in its approach to service provision. A first step is for individuals within the organization to determine how well-established it is in the community by surveying what its "presence" looks like locally, statewide, and/or nationally. That presence often reflects the value that leadership places on the bridge-builders in the organization. If the connections are thin, there is a need to determine why. Making sure an organization has a community presence is the starting point for assisting individuals to strengthen or develop their personal community presence.

Community Participation

Being present in a community is a start, but an organization must also be a community participant. Just as the individuals whom it serves can become active and participating members in a variety of ways – for example, by joining the Elks Club, poetry society or begonia club – so also can an organization participate in its community by supporting local groups. For example, employees can volunteer to staff the Alzheimer's Association fundraiser, or offer technical assistance to the local transportation board, or provide respite services to a sister agency. In doing this, employees can model the community participation they seek to support for people they serve.

Competence

Person-centered planning has gained enormous recognition for focusing on individual capacities (remember, *capacity* – half full or half empty?). Similarly, an organization may create, at all its levels, an ethic of rewarding employee capacities. For example, management may look at the difficult issues of staff turnover and retention, making improvements in the quality of working conditions that communicate the valuing of employees. Or they may step "out of the box" when it is time to make a major change in response to employee suggestions and needs, recognizing that the employees know best what works for them. By supporting and rewarding internal competence, individuals within organizations set the stage to more readily see competence in the people they serve.

Respect

During person-centered planning, individuals are asked to describe a desirable future for themselves. Respecting the individual's response is critical at this juncture, and dictates listening and being responsive to their future as they have described it. Likewise, an organization extends respect when its leadership asks for input about its future from stakeholders, including those whom it serves, its staff, advisory boards, and community members. When organizational leadership asks stakeholders to evaluate its activities, policies, and priorities, and acts on their responses, this indicates respect for those whose lives are affected by the organization. It also supports a culture of listening to what people want for their own lives, and supporting them in realizing their visions.

Choice

Person-centered planning encourages individuals to choose their life path both short- and long-term. Leaders within organizations also make choices about what the organization stands for and how it will express its values and priorities. For example, an organization's board of directors may decide that they can no longer support large residential facilities for people with disabilities, and seek alternatives. Or school district administrators may decide to make social and educational inclusion in the district a priority. When people within organizations choose to look at the needs of the organization's constituents from a new perspective, from a person-centered viewpoint, they are on the way to transforming the organization into one that will ensure that the people it supports are living lives that are being envisioned by and for themselves.

Many organizations are coming to understand that using person-centered planning requires far more than practicing certain techniques with individuals. In many ways, person-centeredness is a direct result of the way in which those working within organizations choose to view themselves and those for whom they advocate. Ensuring that the five concepts described above are integral parts of the organization is a good start in offering person-centered services.

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Living Person-Centered Planning in the Village of Kumbayah

by Shina Asante Ahad and Bahiya Cabral Asante

Eight years ago, after almost a decade of intense community organizing around issues as diverse as keeping a neighborhood fire station open and developing youth leadership, members of New African Voices Alliance (NAVA) evaluated our work and its impact. Our vision was a society where each individual could thrive, where human relationships were based on love and respect, and where both political and economic democracy were the order of the day. However, in looking back over years of work, we recognized that we had lost many people along the way. Their real life needs took them away from working to improve their block, neighborhood, city, and society. Many times, economic needs did not allow them the time and energy for community organizing. People also had pressing family needs, including the desire to actually spend time with their loved ones every once in awhile, as well as the overwhelming needs of children growing up in a world where temptations are many. In the words of the co-founder of NAVA, Shafik Asante, "People are too busy struggling for their economic survival to think about their human liberation."

In a village, children have the combined care of many people, extended "family" members to whom they can go. Person-centered planning works the same way in the village.

Out of this evaluation a new concept was born. Actually, it's probably not new as there is "nothing new under the sun." Yet, it is definitely something we've gotten away from in the U.S. That is the concept of community building or what we in the Village of Kumbayah call *villaging*. As African people, we once believed in the village concept – raising our children in an atmosphere of shared love, support, and discipline. In a village, children have the combined care of many people, extended "family" members to whom they can go. Person-centered planning works the same way in the village. The person in need of support receives it from an entire group of people who value that person and have an emotional investment in his or her growth and success. When it has been determined that someone needs extra support, it is customary for them, their parent/guardian or other key person(s) to present the situation to the gathered villagers. Once the situation has been laid out, a committee may be chosen by the person or people may volunteer. That committee will look into the various options that are available for that particular challenge. Then they will ask the person who is being supported what goals are expected. In this process, we use person-centered planning tools including MAPS, PATH, and Solution Circles. When we have worked with a villager in resolving a problem or plotting a course to a goal, we then have periodic check-ins to make sure that things are moving according to plan and to identify what modifications or additional supports, if any, are needed.

Our most complex experience with person-centered planning occurred when Shafik Asante was hospitalized in 1997. We often refer to Shafik as the heart of the Village of Kumbayah. He combatted cancer for 20 years but still was able to model for us what villaging was all about. In 1994, Shafik did a MAP that was invaluable to us in determining the kind of care he wanted to receive. We knew that it was necessary to provide round-the-clock support, so we came together and drew up a plan. The plan insured that he was never at the hospital alone, that all hospital care that he received was monitored, and that despite his condition, he was always treated with dignity and respect. This was especially critical towards the end of his hospitalization as he was not able to insist upon those things for himself. For example, Shafik always required that doctors treat him as a whole person – speak directly to him, ask him questions, let him know what they were doing. We insisted that these practices continue when he was unable to speak. We made sure that his favorite music was played, that his symbols that he valued were placed around the room, that, in fact, the environment in his room was as close to home as possible. The requirements of his care were shared by all villagers. At the same time this provided needed support to his family and to everyone in the village during this especially painful experience. It was necessary for us to pull together, and we did.

Shafik transitioned on September 5, 1997. Supporting him was the first major test of person-centered planning in our village. We had utilized it before but never in a situation that required so much of all of us or where the person was not able to directly communicate his wishes. We struggled to insure that Shafik's needs, as he saw them, were put first, and for us that is the heart of person-centered planning.

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Planning for Systems Change in Alaska

by Karen Ward, Gordon Ward, Brenda Ross, and Robyn Rehmann

In 1997, a group of people in Alaska embarked on a commitment to effect systems change through person-centered planning. The Alaska Developmental Disabilities Planning Council, the Center for Human Development at the University of Alaska, the Anchorage School District, the Alaska Department of Education, and the Alaska Parent Training Center formed a consortium to give people with disabilities power to determine their own futures. The route to this goal was to increase knowledge, understanding, and use of person-centered planning throughout Alaska's service delivery systems (e.g., schools, community services). Our strategy was to use a "train-the-trainer" approach to build effective teams and partnerships across the state through person-centered planning at all levels of the systems.

In 1997, a group of people in Alaska embarked on a commitment to effect systems change through person-centered planning.

Working with Jack Pearpoint and Marsha Forest, we began training teams in August, 1997. Twelve teams were recruited from school districts, community agencies, and parent groups statewide. Our intention was to bring about systems change by first changing practices so they facilitated the inclusion of all people. We wanted to train teams to incorporate person-centered planning at the individual and school agency levels. By training teams, we hoped members would support each other to build inclusive schools and communities. We also wanted to develop capacity within the state to continue the momentum by developing a cadre of trained facilitators to train new teams, educate others, provide assistance with person-centered plans, and sustain relationships with people from outside Alaska to continually infuse other perspectives.

At this time, trainees are actually using what they have learned as early as 12 months after the initial training. Many have facilitated plans for individuals, families, and themselves. Some are using person-centered strategies at an organizational level to plan better service delivery. Some are incorporating facilitation techniques into other types of training for families, teachers, and service providers. And most importantly, all are coming together with increased energy and enthusiasm that they can make a difference in people's lives. Many participants say that as a result of the training they are more aware and more tolerant, learning to be less judgmental, staying focused on the "big picture" and what is important in the lives of the individuals they serve, developing an inclusive perspective, and not using system jargon. Overwhelmingly, participants say their skills in listening, use of visual imaging, problem solving, communication, and overall facilitation have greatly improved.

We have given people who are concerned about the hopes and dreams of people with disabilities the tools and strategies to better understand and facilitate achievement of those hopes and dreams. There are some things we can do differently to further support the people we have trained. We can support teams so they have time to think, reflect, and develop mindful plans; we cannot expect teachers, parents, and community service providers to do mindful work within the context of doing more with less time. We can pay better attention to multicultural aspects. Alaska is a rainbow of cultures, and each must be respected and preserved. We need to ensure that trainees have opportunities to practice facilitating person-centered plans in a multicultural context. We can provide more practice. Informal follow-up sessions to enable participants to gain more practice, with opportunities to debrief, seem warranted. And all participants wanted more practice using graphics. There seems to be a mystique around the artistic abilities required to portray visual images. Future training must communicate that while graphics are important, artistic acumen is not.

What should we do right now? The basic message we've received is that more training is needed and should be marketed to a wider audience. The power of person-centered planning is not limited to persons who experience developmental or other disabilities – we all benefit. To effect systems change, we need to ensure that administrators, parents, and individuals who experience disabilities are more broadly represented and trained.

We think we are on the right track. Training is a process, not an event. We are not just teaching person-centered planning, we are helping to build collaborative teams. Alaska has just begun its journey, but the goal is in sight!

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A Person-Centered Approach to School System Planning

by Ken Woodley

Most large organizations, including school districts, are, by their very definition, a mix of people, environments, locations, and workplace cultures. For this reason, planning in such environments has been a daunting challenge for those charged with the responsibility of providing leadership and strategic direction. The focus of much planning has been to control, direct, and mold the constituent elements of the organization into one person's particular vision. The end result has often been dismal. Lack of correlation between outcomes and plans, apparent lack of employee "buy-in", and a sense of futility coupled with a reluctance to initiate planning activities have been frequent, unfortunate outcomes.

Planning in school systems has often meant the application of highly developed "models" taken from other contexts. These models have usually had, at their cores, overwhelming concern for money, targets, efficiency (usually related in cost-effectiveness terms), and a myriad of other measurable and observable descriptors. Unfortunately, in the rush to get things done, educators have simply accepted such models and transferred them to the school environment without critical analysis of the contexts that gave rise to them, and judgement about their appropriateness for school systems.

Our school district has had to realize the increasing importance of planning as a means of responding to the heightened call for accountability coming from all quarters of the public sector. It is obvious that changes resulting from economic variations, technological advances, demographic shifts, and countless other uncontrollable variables are not going to diminish. The truism of "change being the only constant" is upon us. So, we have turned toward improving the effectiveness of our planning.

In working with staff on small projects, we had started to notice that the planning process moved along more quickly and productively when staff were empowered. We found that locating major portions of the planning process in the hands of those who were going to have to carry out the plans paid big dividends: The focus immediately shifted from questions of power, compliance, rights, and the like to discussions of substance centered on the items under consideration. Teachers moved away from asking questions such as, "Who is responsible for disciplining students caught fighting?" Instead, they started asking questions like "What does a safe school look like for our students and staff?" The caliber of discussion and the resulting plans improved dramatically when people were empowered. Consideration for students and their needs became much easier when the planners felt they had been considered. It was as if they had been freed to go beyond themselves and to engage in professional altruism.

Our experiences slowly led us to understand a critical element of our organization. We had been created to deliver services to individuals, and our major budget expenditure was on personnel. Because of this, "people" needed to be a major focus in all that we did. This realization allowed us to start viewing and treating people as an investment instead of a cost item. We began to understand that more significant gains were to be made if we put our people at the center, and that this approach delivered greater results for those we sought to serve.

A focus on people has proven critical for us because it has allowed planning to incorporate the individual assumptions and premises of those who will have to follow through on the plans. When planning is focused solely on results and budgets, it leaves important human dimensions untouched. Centering planning on people allows for significant human motivators to become woven into the process, thereby heightening the likelihood of commitment and success.

Focusing the planning process on people as opposed to things has allowed us to plot major change in the direction of our organization. Our commitment to people-centered planning resulted in our adoption of the PATH model for planning in all of our schools. Involving staff and students, and letting them have a major role in shaping the future, has resulted in plans that will yield far greater benefits to our district than would have occurred through more conventional strategic planning approaches. Knowing that their own needs are being considered, staff and students have been able to come to new understandings about the future, and to commit to a planning vision that has been enriched through everyone's participation.

The impact of this shift in our district's culture has been felt on the individual level, as well, including in the way we work with students who have developmental disabilities. Our previous culture tended to be at odds with the use of person-centered planning to help students identify dreams and plans for their own lives. We would have been more likely to ask questions about costs and resources than about personal journeys and circles of support. Now, our entire district is better able to support students with disabilities in accessing and realizing their personal visions by traveling with them as they grow and change. We have now become a community that listens and responds to individuals' dreams and needs.

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It's for All of Us, or Not at All

by Andy Smith

Another day, another phone call. Someone will inquire if we can teach their organization about person-centered planning. In reply, we will tell them that for four years we have been working with organizations that provide support to groups of people who are at risk of social exclusion. We will tell them we have run learning groups for facilitators, families, and people who use human services, and that person-centered planning has been something that we have found works in a variety of ways. We will also keep in mind that we have seen some people and organizations use person-centered planning tools and techniques as fashionable replacements for the disempowering systems they used before. As a result, some people with disabilities have experienced person-centered planning as yet another imposition delivered by the service world.

Some people with disabilities have experienced person-centered planning as another imposition delivered by the service world.

We have realized the vital importance of three core principles regarding the use of person-centered planning: We all need support, we are all ready, and we all need to dream. Without careful and constant adherence to these principles, we are in danger of inflicting powerful processes on others without actually understanding the impact this has. The end result can be disastrous at worst, and a meaningless paper exercise, at best. The following examples show a brighter side of the picture in Scotland today and highlight the importance of *principles* over planning *processes*.

We All Need Support

One professional who participated in our facilitator training for person-centered planning was unhappy with her work as a manager of community health care providers. She was working for an organization she knew was moribund and felt unable to move forward. As a facilitator who already worked in a person-centered way, she brought this problem to our learning group. Together we worked out a plan with her and a few close friends she had chosen. The PATH she then developed held together that unique blend of the ordinary and the profound which is at the heart of all our futures. Through a careful process of combining both her vision for the long haul and realistic, practical goals, she gained the resiliency to leave her work and set up a business in an entirely different field. She also now works part - time as an advocate and facilitator.

Another member of our facilitators group used the MAP she developed for herself as a means to find the strength to tackle the management in her organization. The organization and she herself had seen her job as recruiting volunteers to help out. Following her MAP allowed her to feel able enough to persuade the organization to re-employ her as a community builder. Her job now is one of enabling the mutual exchange of gifts between people using her service and others in the wider community.

We need to realize that at certain times in our lives (whether we use services or provide them) we will need the help and support of friends, family, and colleagues to help us articulate our dreams and aspirations. Organizations that are open to using person-centered approaches within their teams can more deeply appreciate universal needs and how we sometimes must liberate energy and commitment among those who support us in order to help us meet them.

We Are All Ready

We worked with an organization that supported people who have learning disabilities, and which was facing major change. But, it was also open to seeing everyone as potential contributors to shaping the future. Four individuals who used the service were trained together with a small group of staff using tools like Essential Lifestyle Planning and MAPS. Everyone was able to help on everyone else's personal plan. We knew that the question "Are people with disabilities – specifically, the people *we* serve – really ready for person-centered planning?" was one that many professionals raised. We learned quickly that some staff were less ready to work out their own future plans than the people who used their services – less ready, that is, in terms of feeling strong enough to look at change head on. For instance, the willingness of one of the four individuals to explore his own dreams and nightmares encouraged an employee of the service to begin the dreaming process himself, and eventually he found a new job supporting people to leave a large institution. Another of the four was ready to engage in the planning process, but she felt alone because she felt unable to share her dreams with her family and had few real friends with whom to talk. As the planning advanced, people rallied around her because they knew that the issue was not the need to wait until she was ready, but the need to provide a different type of support to her now. They wanted to discover ways to build her strength together, and by doing that she was eventually able to explain to her family what she really wanted.

We have inherited a legacy of thinking about people who are now socially excluded which tells us that only when people can prove their readiness for change through the acquisition of skills, abilities or behaviors can they take a place on our society. Organizations can invalidate the readiness of some people who have been patient for a long time. By

using person-centered approaches throughout organizations we can better understand organizational unreadiness and our own fears about change.

We All Need to Dream

For all of us, our dreams expand the space into which we can move. There come many times in all our lives when the right thing to do in the moment is to imagine new possibilities. Yet, for people with developmental disabilities and their families, dreaming has been something the rest of the world has consciously and unconsciously forbidden them. They have been told that the life that children with disabilities can have compared to the life others live will not be the same. In addition, families have often been let down, time after time, by the service world.

Spending time with several families recently we worked to help nurture the dreams of young people with disabilities as well as the dreams held by members of the families, and then shared these together. One father dreamt of having more time to explore his interest in water color painting and work for his church. His son dreamt of living on another planet where he could go anywhere easily just by pressing a button – a place where there was a chance to hang out with his friends, play pool, and play his music loudly. When the father listened to the son's dream, they were able to see the power of each others' dreams and the need to fulfil them.

Organizations sometimes fail to make the connection between dreaming that happens within the organization and the dreaming of the people they serve. Organization leaders may dream of mission and vision; other individuals working there may dream of promotions, new careers, or a better world. If organizations explore mutualities between these dreams and those of people they serve, they can experience an increasing sense of solidarity in our common humanity.

In Pursuit of Shared Meaning

Over and over again we have seen and heard about people receiving so-called person-centered plans where the emphasis has been on the solutions that have emerged or on how the person's life has changed. Outcomes are important, but many person-centered approaches are powerful in part because they harness creativity. If there is enough of this energy around then things might happen. However, the power of person-centered planning can be misused and result in sophisticated control programs if there is not an understanding among the people facilitating about what thinking in this way means for us all.

The greatest power in all the processes we use arises not just from some neat and clever ordering of questions, but from the creation of a shared understanding about where a person might be, who they really are, the gifts and dreams they have, and the support they'll need to make a new future possible. The only way we know how to teach this well is to help everyone involved develop a shared sense of these core qualities that we all have in common. We do this by first helping the people who make up organizations plan for their own lives, whether they be parents, professionals or whomever. In this way, organizations can learn that at the heart of a person-centered philosophy is a deep respect for all our hidden talents, unspoken aspirations, and interdependence. For facilitators, this means regularly planning for ourselves, and with our friends and family. By doing this we learn to develop a sense of compassion based on commonality, not pity. Following on from this we become more aware about how to generate empathy when planning with others, which is a prerequisite to making real, sustainable change possible.

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Taking a New View ...

"If Maureen died tonight," I asked them, "who would care?" Someone said her mother probably would. Anyone else?" I asked. The group thought about it and decided, "Not really." So this woman who has no home, whose one emotional relationship with someone other than her mother has been abusive, who makes about $5 a week, and who has no friends is difficult to be around. In the face of all this – by the way of comfort and assistance – she is told that if she is "appropriate" she can earn two cans of diet cola a day. And then we get confused when she is still noisy, demanding, and "impossible"....It took me awhile to notice the perilous gap between what we know and what we do. Knowing her plight as a homeless, poor, and battered woman would ordinarily move people to think in terms of getting her some emergency money, a reliable income, and a safe home. Instead, because of her labels as "mentally retarded" and "emotionally disturbed," she was seen as needing "treatment"....

Where hurt has been, there is fear; fear and love cannot live in the same house; and where there is no love, there must be control. This powerful syllogism can help us understand the lives of people with disabilities and our own, as well. If we are to be of help to others, we need to understand our own lives.

Excerpted with permission from Lovett, H. (1996). *Learning to listen: Positive approaches and people with difficult behavior.* Baltimore: Paul H. Brookes Publishing. Pages 2 & 224.

What's Most Important? 'Tis People . . .

by Te Ripowai Higgins

Hütia te rito o te harakeke
kei hea te kömako e kö?
Rere ki uta?
Rere ki tai?
Ki mai koe ki ahau
He aha te mea nui o te ao?
Mäku e ki atu:
He tangata, he tangata,
he tangata!

Pluck out the centre shoot of the flax bush
where would the bellbird sing?
Should it fly inland?
Should it fly to sea?
Ask me
What is most important in the world?
I would say:
'Tis people, 'tis people,
'tis people!

This proverb I share from my culture, from my land, from my ancestors, the Maori (aboriginals) of Aotearoa/New Zealand. Proverbs by their very nature use metaphors to convey the heart of their message. They are intended to generate analysis, interpretation, reflection, and ultimately action. This proverb has a message that's simple yet powerful.

Flax is a familiar plant on the Aotearoa/ New Zealand landscape, growing in clumps of sword-like blades in a fan formation. It has inspired many Maori proverbs, and is used as a metaphor for the family. The *rito* (center shoot) is the child, protected on either side by its "parents," and the outer blades are the "extended family." All have a role to ensure the survival of the plant. In Maori culture, grandparents/parents are not just biological, but all those generations who are collectively responsible for the nurturing and care of the child. The grandparents' generation have special and critical responsibility for the child's mental, spiritual, educational well-being; the parents are focused on ensuring physical well-being. A traditional Maori *whanau* (extended family) can range from 30 to 230 members.

Flax was and continues to be used by Maori for weaving and medicine, therefore care must be taken to ensure the center three blades are protected. Let's explore this metaphor. The *rito* (centre shoot) is the most vulnerable member of the community. The embracing outer blades are all critical for it's well-being. When blades are cut for weaving, only the very outer blades are removed. Like the extended family, flax has many blades, each with its own distinctive character and place in embracing the most vulnerable parts. As with life, so comes death; the soil gets nourishment and the root system remains healthy. Those departed continue to play an important part in the life of the vulnerable. They are the guides, the exemplars.

The bellbird (an outsider) is also an integral part of this community. When it seeks nourishment from the flower, it pollinates and strengthens the plant with new genes, new gifts. Like the bellbird, the good facilitator of person-centered planning nurtures the gifts of the people and guides them in the direction of their dreams.

The power to decide the fate of this plant belongs to the human element – the weavers. Our weavers are like sympathetic facilitators. They have power, and in setting guidelines they shape whether the flax (or people) will be given the chance to learn with future generations. The weavers, with their customs and cultural practices, set the framework, remind us of opportunities, and hopefully ensure that the flax survives.

A weaver can turn flax into an ordinary object or a fine piece of art. A person-centered planning facilitator can manage the warehouse (doing it like its always been done) or create opportunities for human magic and art (doing something new and creative). We can create circles where all benefit and learn, and the place of each is respected.

Nevertheless, I must pose the unthinkable question. What if a better, stronger, more durable material is discovered? Will the weaver relinquish their relationship in this cycle? Will we abandon the flax and drain the swamp? Will we abandon the weaver? The proverb teaches us to stop and think before we act. That is its purpose – to continually challenge and remind us of the consequences of our actions.

Today, Maori people are struggling to maintain our traditional society and natural community – the *whanau* (extended family). One hundred and sixty years of colonization and assimilation policies have driven our culture to the brink of destruction. The more communities have become isolated from each other, the more the spirit of defiance and resistance is becoming the renaissance of Maori culture. We understand this by learning from another proverb:

He tihi maunga e pikihia
He tihi moana e ekehia
He tihi tangata e kore
e pikihia, e ekehia
he tapu, he tapu

Mountain summits are conquered
Mountainous oceans are conquered
The summits of the human spirit will
never be conquered
for it is sacred (unconquerable)

It is that unconquerable spirit of the human species that needs to be strengthened. We must challenge and give hope for communities and people to take back control from the "professionals" to themselves. This is not simple to do or even say, but it is right and it is time.

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Resources About Person-Centered Planning

- **People, Plans and Possibilities** (1997). By H. Sanderson, J. Kennedy, P. Ritchie, with G. Goodwin. This book provides a comprehensive overview of the history and practice of person-centered planning, looking at five planning tools commonly used and their impact on the lives of individuals as well as organizations. Available from SHS, Edinburgh, United Kingdom • (44) 131-538-7717 (voice), (44) 131-538-7719 (fax).
- **Waddie Welcome: A Man Who Cannot be Denied**. This 26-minute videotape is the story of a man born with cerebral palsy in 1914. For over 60 years he lived surrounded by the love and care of family and friends, but after his last surviving brother died he was placed in a nursing home. He resolved to live once more in a home with a family with children, attend church, interact with people, and contribute to his community. His personal vision was supported by a circle of friends and after over two years of person-centered planning, they brought his vision to reality. Available from Program Development Associates, Cicero, New York, 800/543-2119 (voice), 315/452-0710 (fax).
- **PATH Training Video: Introduction to PATH.** (1994). By Inclusion Press and Parashoot Productions. This 35-minute training video shows PATH with Joe, a man who has cerebral palsy who is moving from a small institution to his own apartment. The videotape illustrates the eight steps of the PATH process with Joe, his family, and friends. Available from Inclusion Press, Toronto, Ontario, Canada, 416/658-5363 (voice), 416/658-5067 (fax).
- **PATH Workbook** (2nd edition, 1993). By Inclusion Press. A workbook and guide to the PATH process. PATH is an eight-step planning tool and problem-solving approach that involves dreaming from the future and ending with an action plan for the present. Color graphics are included as an example. This is an essential tool for anyone thinking about or using PATH in person-centered planning with individuals, families, or organizations. Available from Inclusion Press, Toronto, Ontario, Canada, 416/658-5363 (voice), 416/658-5067 (fax).
- **MAPS Training Video: Shafik's Map.** (1996). Produced by Inclusion Press and Parashoot Productions. This 35-minute videotape shows a family going through the MAPS process and provides insight into what is going on behind the scenes in the life of the family. Available from Inclusion Press, Toronto, Ontario, Canada, 416/658-5363 (voice), 416/658-5067 (fax).
- **Learning Listen: Positive Approaches and People with Difficult Behavior** (1996). By H. Lovett. Observations about the ways in which persons with "difficult behavior" are responded to by individuals and systems. Available from Paul H. Brookes Publishing Co. (U.S.), 800/638-3775 (voice), 410/337-8539 (fax); Irwin Publishing (Canada), 800/263-7824 (voice), 905/660-0676 (fax); Jessica Kingsley Publishers (U.K., Europe, Middle East), 44-0-171-833-2307 (voice), 44-0-171-837-2917 (fax); and MacLennan & Petty Pty. Ltd. (Australia, New Zealand), 61-2-9669-5755 (voice), 61-2-9669-5997 (fax).
- **Circles of Friends: A Peer Support and Inclusion Workbook for Secondary Schools** (in press). By D. Wilson and C. Newton. This book outlines the values, philosophy, and rationale of Circles of Friends for educators who share a commitment to full student participation in the school community. It addresses the stages of planning, setting up, and running a Circle within a secondary school setting, and outlines the pitfalls to be avoided and the opportunities available for supporting the social inclusion of vulnerable students. Available from Folens, Dunstable, United Kingdom; the e-mail address is Folens@Folens.co.uk.
- **Remembering the Soul of Our Work** (1992). By C.L. and J. O'Brien. This book of stories by staff members of Options in Community Living focuses on the human side of supporting people in building community – the joys, frustrations, victories, and dilemmas. Available from Options in Community Living, Madison, Wisconsin, 608/249-1585 (voice), 608/249-3372 (fax).
- **It's My Meeting! A Family/Consumer Pocket Guide to Participating in Person-Centered Planning** (1996). By D. DiLeo. This booklet describes person-centered planning and how families and consumers can make use of the process. Available from Training Resource Network, Inc., St. Augustine, Florida, 904/823-9800 (voice), 904/823-3554 (fax).
- **Mapping Inner Space: Learning and Teaching Mind Mapping** (1991). By N. Margulies. A guide to mind mapping, a form of graphic representation that enables users to capture information in a visual format that clearly conveys the essential concepts and relationships between them. This is a useful tool in a variety of planning processes. Also available is **Maps, Mindscapes, and More** (1993), a 90-minute videotape demonstrating visual-spatial techniques for graphic representation of ideas. Available from Zephyr Press, Tucson, Arizona, 800/232-2187 (voice), 520/323-9402 (fax).
- **Essential Lifestyle Planning Website** (http://www.napanet.net/business/personal/ASA/friends.html). The section titled Michael Smull and Friends contains over a dozen documents on various aspects of Essential Lifestyle Planning.

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giving strength to the directions desired by the central individual. By doing so, we have stood behind our ethic that "normal" is not always best, and "usual" is not always the way things have to be.

In this, we have added our voices to other voices of the latter part of this century who are speaking against our cultural and political myopia. We are asserting that diversity in all of life is of great value, and that we plan to keep it as a regular part of our communities.

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others who are involved in the process, rewarding individuals for challenging the status quo and the tendency of all of us to continue doing things the way they have always been done, and a realization that person-centered planning is hard, messy, and an ongoing process – a process that offers no guarantees, but provides people with a roadmap to follow on their journey to a better future.

Counting the Costs

The question, "What are the costs?" is not one to which we can provide a direct answer. Although such a query might appear justifiable from an administrative standpoint, the idea of affixing costs and placing limits upon the resources people have available to live the lives they envision for themselves is inimical to the basic core of person-centered planning. It is true that to effectively facilitate people coming together and working collaboratively to support others, time and energy are necessary. It may also be the case that what is needed to support a person reaching his or her vision for the future is not available and must be created, requiring even more work. The time and effort spent in these endeavors, however, should be thought of not as costs, but as investments – investments in a person who has the right to live adult life as he or she wants, not as others expect.

Considered in this manner, the real question is, "What is the cost of failing to plan in a person-centered manner?" Our most concise response to this question is, "enormous." Failing to offer opportunities for persons to create visions for the future and direct their own lives means that individuals are unlikely to have the chance to develop to their fullest, and to use their gifts and capabilities to enrich the lives of others. It means we have abrogated our responsibilities as professionals and as persons to support our fellow humans, and that, as a whole, our society is diminished. Thinking about costs in this way, it becomes clear that we cannot afford to plan and provide support services in a manner that is anything but person-centered.

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sustain us on that life journey. MAPS and PATH do not guarantee we will achieve our dreams; they do help us to live our lives on a journey of hope, accomplishment, and wonder.

Critics say that MAPS and PATH are not accountable because they are not purely responsive to the needs of bureaucratic structures. We disagree. They are profoundly accountable. The stumbling block is accountable to whom? Person-centered planning tools are accountable to the individual, family or team on whom they are focused. Some critics are also concerned that MAPS and PATH are "individualistic." We believe they are personalized and promote interdependence. Substantial portions of the tools look at who is in our circle (our lives), who we need to enroll, and what specific actions we have to take over time to make our dreams happen. All of these rings explore and develop our interdependence rather than our isolation.

Do MAPS and PATH always work? No! A plan is simply that – a direction with a hope that something will happen. There are no guarantees. When person-centered planning tools are used correctly with the spirit of the heart, they are *never* about a person in isolation and *always* about a person (or a family or group) in a context of interdependence. The plan mobilizes that network of people to be part of the implementation. The illusion that the PATH (or any other tool) is done or completed after two hours or a day is a misrepresentation of the essence of the tool. The plan is not done because it is posted on the wall or placed on a chart. It is completed when a person lives it.

Seeing Differently

MAPS are PATH are about focusing on human beings to help design and develop plans for their future. They are for all people. If we see people as "clients," "consumers," or "special ed students," or if we assert power over people, we are not doing MAPS or PATH. These tools are for human beings – not labels. This is full of paradox because it is simultaneously a very simple concept and enormously difficult to implement. It requires us to challenge and refocus values that we "learned wrong" and must "relearn." This is hard but necessary work.

The artist, the architect, the musician, the poet, the writer all have much to teach us about person-centered planning. A sculptor sees a piece of art in the raw stone or wood. An architect envisions a building when overseeing a naked piece of earth. A musician hears a score in the breeze and in her head. So, too, the artist of person-centered planning sees the full human being through

the layers of societal rules and norms that have often corroded and encased the human spirit.

People with disabilities have often been buried under a ton of labels and phrases that mask who they are. The more oppressed and vulnerable the "human being" the more talented and sensitive our artist facilitator needs to be. Person-centered planning is, in essence, listening and sharing vulnerability. It is about sharing life, sharing power, giving up control, encouraging interdependence, and getting to what really matters to makes someone's life not perfect, but meaningful. It is about nourishing the humanity and gifts in each of us.

It is about sharing life, sharing power, giving up control, encouraging interdependence, and getting to what really matters to makes someone's life not perfect, but meaningful.

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working? What have we learned? What have we tried? What else could we try? What else do we need to learn? Ask these questions often and in as many ways as makes sense. Write the answers on the person-centered plans. Where this is done those who provide the support see what they learned incorporated in the plans. They see that what they do and how they do it changes as we all learn. Those who are supported and those who provide the supports feel respected, and part of a partnership. The plan becomes a living document that is changed as our understanding deepens and as the person changes.

Starting Small, Sustaining Change

If we want to change the system we need to look for incremental change as well as revolutionary change. At any moment, we can create best practice for a few people with enough effort. However, if the many are not to be left behind we need to move our entire system incrementally toward best practice. One way to do this is to think of the changes as happening in phases. Start by looking for every opportunity for best practice and seize each one. Then think about how to start incremental change. For many it begins with simple person-centered plans where we ask what is important to people in everyday life, compare that with how they are living now, and change what can be changed now. Change what can be changed without having to make major changes in structure or practice.

Making the easy changes is a good way to start, but an unacceptable place to stop. If people with disabilities are to get the lives that they want, change has to continue. Planners, managers, and those who support have to look at what people want and compare that with their capacities to deliver what is being asked for. Where there is a deficit in capacity they need to look at what needs to change. Does the deficit in capacity reflect a deficit in skills, knowledge, or competencies? Does the development of new capacity require changes in policy, practice, or structure? Is the deficit a reflection of problems in how we think or in the unwritten rules for how we act? Is there a problem with organizational culture? Again, this is most easily seen as a learning wheel where we are looking at what individuals want and using that to change the system.

The change literature makes it clear that there is no change without loss, but we can make change without wreckage. We need to make sure that those who provide the supports are offered the technical assistance to find the win-win solutions. Most will need help to learn the new skills and make the changes in practice and culture needed to move from a relatively static system of supports to one that has the flexibility needed to support people in their evolving visions of how they want to live. They will have to change provider agency culture that sees the funding that people receive as the agency's money and uses the language of ownership about people with disabilities. Policy-making bodies that mandate person-centered planning will have to make changes in funding, practices, and structures affecting agencies if plans are to reflect what individuals want over time and be implemented. And we all must support a new vision of quality and build structures that are rooted in values of respect, trust, and partnership.

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